

# Progress in Palliative Care

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## Editorial

# Spirituality as an essential domain of palliative care: Caring for the whole person

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Since the beginning of hospice and then the development of palliative care, spirituality has been recognized as an essential element of palliative care. Cecily Saunders<sup>1</sup>, the founder of hospice, dedicated her life to the care of dying patients by attending to the 'total pain' of the patient, a term she described as encompassing spiritual distress as well as psychosocial and physical distress. Her model was eventually described as the Biopsychosocial spiritual model, which is the framework for palliative care.<sup>2</sup> The model emphasizes the totality of a patient's experience in the context of their illness and/or dying. In this model, spirituality is an equal domain of the care of patients and families. The American College of Physicians, in response to the work of Sulmasy and others, noted that physicians have the obligation to attend to all dimensions of the patient's illness experience – the psychosocial, spiritual, and existential suffering as well as physical pain.<sup>3</sup> In 2004, the National Consensus Project and the National Quality Forum, through a consensus process, defined spiritual, religious, and existential issues as a required domain of palliative care.

Over the last 25 years, there has been considerable research in spirituality and health, and specifically in spirituality and the care of seriously ill patients.<sup>4-6</sup> These studies have demonstrated an association of spirituality and/or religion with a variety of health outcomes, including quality of life, coping with suffering, and distress. Surveys have also indicated a strong desire on the part of patients to have their spirituality addressed in the clinical setting and integrated into their care plans.<sup>7,8</sup>

In spite of Dr Saunders pioneering work, recognition of the spiritual domain as part of the care of patients, and the increased body of scholarly writing

and research in spirituality and palliative care, this domain of care has been overlooked.<sup>9</sup> The focus of hospice and palliative care has been largely on attending to physical symptoms and psychosocial issues. In part, this has been because of a lack of a common definition of spirituality as well as ethical concerns regarding roles of providers in this seemingly personal area of clinical inquiry. Furthermore, the role chaplaincy has not been clearly understood by clinicians. This has contributed to clinicians' apprehension of addressing an area in which there may be no clear way to treat and alleviate spiritual concerns and issues. Clinicians also have practical concerns regarding time, expertise, and ways to integrate spirituality into a medical model of care. Finally, while there has been considerable progress in curricula in spirituality and health,<sup>10-13</sup> there is great need for standardized education programmes for all clinical disciplines in spirituality and health.

To address these concerns, the National Consensus Conference entitled Improving the Spiritual Domain of Palliative Care was convened.<sup>9</sup> An interdisciplinary group of palliative care clinicians, chaplains, clergy, spiritual directors, and others developed guidelines for implementing the required domain of palliative care – spiritual, religious, and existential issues. The conference attendees developed a definition of spirituality and spiritual care as well as an innovative implementation model; guidelines on assessment, treatment and care plans, and education; interdisciplinary team functioning with regard to spiritual care; and recommendations for quality improvement research in this area. The attendees highlighted the need for immediate recognition of and attention to spiritual distress, which should be responded to with the same intensity as physical pain. The conference also endorsed the important role of the board eligible or board certified chaplain as the spiritual care specialist in clinical care with the other clinicians being the generalists, in a generalist-specialist model of care.<sup>14</sup> Finally, the participants cited the importance of

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spiritual development as part of clinicians' professional development, noting the role of spirituality as part of professionalism, specifically for a vocation-driven professions. These recommendations are currently being used by organizations, nationally and internationally, as a basis for integrating spirituality into healthcare systems especially in palliative care. There are also national demonstration projects in California and elsewhere that are piloting these guidelines, developing tools, and testing integration methods of spirituality into care.<sup>15</sup>

Spirituality, defined by the consensus conference, is, 'the aspect of humanity that refers to the way individuals seek and express meaning and purpose, and the way they experience their connectedness to the moment, to self, to others, to nature and to the significant or sacred.'<sup>9</sup> This definition underscores the universality of spirituality – all people seek meaning and purpose in their lives. This search becomes more intensified when people are dealing with serious illness and especially when they are faced with the prospect of dying. In those times, especially the longing for the ultimate, transcendent meaning and purpose becomes evident. People need connection to others as well as a connection to something outside themselves. The connection to something outside themselves may be manifested as a significant experience or as the sacred, or holy, however, people experience or understand that. It could be a philosophy, belief, values, or a relationship with God, a higher power, or a concept that give people a sense of meaning, purpose, and value that transcends illness, pain suffering, and loss.

Spiritual care is not about fixing and resolving spiritual distress with a pill. It is instead the recognition that people can find healing within themselves, even in the midst of dying. This process is rooted within the relationship between the patient and the clinician. The clinician–patient relationship, one that is intimate but with formality, is the mechanism by which healing can take place. Clinicians partner with patients as patients deal with suffering, loss, and illness. In that partnership, it is both the patient and clinician that are transformed. This is one reason as to why spiritual or reflective formation should be part of professional development.<sup>16</sup> Spiritual care emphasizes the role of compassionate presence as therapeutic. The clinician who listens intentionally and with full presence creates an environment of trust, where the patient, sensing respect, and dignity, can share what is of deep concern. In so doing, the patient can find the understanding and clarity in which healing becomes an opportunity. The clinician can connect with their inner sense of call to a healing profession.

Healing can be defined as the patient finding a way to cope with suffering, or a way to utilize his or her

beliefs to feel better, or make the appropriate adjustments in their life to find peace and wellbeing. It can result in a greater sense of coherence, meaning, and purpose. It may also impact on resilience and buffer against the negative effects of stress. Spiritual care emphasizes whole health even in the midst of serious disease and dying. The focus is shifted from disease to health and wellbeing. Spiritual care, therefore, is at its root, honoring the dignity of each person and providing care that is based in compassion. The skills that extend from this root are communicating about spiritual concerns with patients, identifying spiritual distress, and integrating patients' spirituality into treatment and care plans with the expertise of the chaplain or other spiritual care professionals.

The notion of spiritual distress as a diagnosis has raised some questions about theologians, chaplains, and others who recognize the complexity and expansiveness of the human spirit and of the transcendent. Reverend Joep van de Geer has shared a model (Fig. 1) in which the spirituality domain is seen as the core of the person. While the centre of the spiritual domain is perhaps beyond any person's understanding, the place where spirituality intersects with the physical, social, and emotional domains may be where the presentation of and diagnosis of spiritual distress occurs.

Spirituality and health is a relatively new field of clinical care. While much progress has been made in identifying guidelines, models, and diagnosis codes for spiritual distress, much more scholarly, clinical, and reflective work is needed. Spiritual distress should be more clearly defined with taxonomy around spiritual diagnosis. Treatment or care plans need to be better defined with measured criteria and outcomes. This moves the area of spirituality and health in a reductionist manner. The narrative of patients and the subsequent wholeness of that spirituality, however, cannot be lost while we utilize reductionism to better integrate spirituality in clinical settings i.e. making it more accessible in care. The challenge for the future will be to do both: care for that patient by listening to the narrative with compassion, while using our clinical skills to diagnose

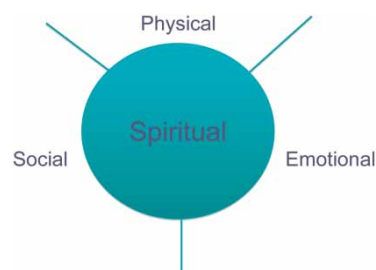


Figure 1 The biopsychosocial spiritual model of care.

and treat the total pain of the patient – spiritual as well as psychosocial and medical.

This issue of *Progress in Palliative Medicine* is dedicated to the whole person approach to care. This approach recognizes spiritual care as based in compassionate relationships in which dignity and respect by the clinicians can lead to healing and a sense of health in the midst of serious illness and dying. We also balance this with practical recommendations and research, which helps clinicians and health system-integrate spirituality more fully in the clinical models of care.

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